

Investigation of parents with high-risk infant on participation in care, depression, quality of life, and anxiety according to the infant's severity of neurologic impact

Investigation of parents with high-risk infant

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Abstract

Aim: The study aims to examine the psychological consequences such as anxiety levels, quality of life, depression, and participation in the care of parents with high-risk infants who have varying levels of neurological impact severity.

Material and Methods: Forty high-risk infants and their mothers were included in the study. The infants were divided into three groups according to the Dubowitz Neurologic Assessment Scale. The State-Trait Anxiety Inventory (STAI), Edinburgh Postpartum Depression Scale (EPDS), Quality of Life Short Form 36 (SF-36), and the NICU Care Participation Scale were administered.

Results: There were significant differences in the mothers' anxiety and depression levels ($p < 0.001$) and many parameters of quality of life according to the severity of neurological impact. However, it was determined that the severity of the neurological impact did not affect the mothers' participation in care ($p > 0.01$).

Discussion: Although our study revealed that parents' depression, anxiety, and quality of life levels changed according to the severity of neurological impairment in high-risk infants, care participation was not affected. The limited sample size and the inability to generalize the results to different cultural and socioeconomic groups are important limitations. Nevertheless, it can be concluded that the medical condition of the newborn seriously affects the mental health of the parents.

Keywords

Family Caregivers, Neonatal Intensive Care Unit, Postnatal Depression, Quality Of Life, Anxiety

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Introduction

A high-risk infant is defined as an infant that requires more than the standard monitoring and care offered to a healthy full-term infant [1]. When a high-risk infant is born, compared to a healthy newborn, medical, psychosocial, and economic problems may occur [2]. The relationship between the parental mental health of infants hospitalized in the NICU and infant outcomes has drawn attention to numerous studies published in the last decade. These confirm the clinical observations that parents of NICU infants experience increased acute stress, anxiety, depression, and post-traumatic stress during and after NICU hospitalization. The psychosocial problems seen in mothers with infants in the NICU can be listed as sadness, guilt, and anxiety [3-5]. The results of the psychological problems experienced by mothers with infants in the NICU can be listed as difficulty in establishing the mother-infant bonding, negative development of the infant, and a decrease in the mother's quality of life [4]. Gerstein et al. reported that increased stress and depressive symptoms in mothers with high-risk infants affect the parenting behavior of the mother even 5 years after discharge from the NICU [6].

Studies investigating parental mental health about neurodevelopmental outcomes have focused almost exclusively on cohorts of preterm infants [7-9]. Only one study has demonstrated an association between neonatal encephalopathy and maternal postpartum depression [3]. When the literature is examined, no other research has been found that distinguishes infants according to neurological deficits and examines mothers. It remains unclear how parental psychological distress relates to factors such as the infant's risk of readmission to the hospital, length of stay, or course and severity of illness in the NICU or after discharge [10]. According to WHO, newborns are seen as biopsychosocial beings, and this new paradigm is considered to be the beginning of parents to develop a more active role in the upbringing of their children. In recent years, parents have been encouraged to participate in NICU care skills. With this participation, a lower mortality rate and severity of neurologic impact were found, as well as lower parental stress rates [11]. However, first of all, it is necessary to reveal the participation of parents in care and the affecting factors. Therefore, it was aimed to examine the levels of participation in care, depression, quality of life, and anxiety according to the severity of the neurologic impact on the parents who have a high-risk infant.

Material and Methods

Study Design and Participants

A cross-sectional study was conducted between October 2020 and June 2021 on 40 parents and their high-risk babies in the tertiary NICU of Afyonkarahisar Health Sciences University Hospital. The sample size of the study was determined by power analysis. Using the G*Power program, the alpha value was set at 0.05, the effect size was 0.5, and the sample size was 40 with a universe representation power of 0.9281. The study included 40 infants born between 37 and 40 weeks of gestation and weighing less than 2500 g who were in the NICU for at least 10 days after birth and were diagnosed as infants with neurodevelopmental risk. Forty parents who were older

than 18 years of age, had adequate communication and reading skills, and did not have a serious physical or mental illness were included. Infants of families who refused to participate in the study and infants with congenital anomalies and severe sepsis were not included in the study.

Data collection

To determine the neurological impact of infants, a Dubowitz Neurological Examination was performed by specialist health personnel 6-48 hours after birth. Clinical diagnosis and Apgar score were noted, and reflexes and muscle tone were evaluated. To obtain comparable results, all infants were tested under the most equal conditions possible, with attention to feeding time, sleep, and irritability.

Demographic information, including the parents' age, marital status, and education level, was obtained. Additionally, participation in care, postpartum depression, quality of life, and state and trait anxiety were evaluated.

Measurement Tools Neonatal neurological examination data, including birth weight, gestational age in weeks, birth length, head circumference, Apgar scores at the 1st and 5th minutes, clinical diagnosis, diet, presence of abnormal reflexes, need for an assisted breathing device, muscle tone, presence of epileptic seizures, and information about the problem, interventions, and length of stay in the NICU, were obtained from hospital files. Values from the 5th-minute Apgar scores were categorized as follows: 0-3 as low, 4-6 as moderate, and 7-10 as normal. Since our study had no infants with low Apgar scores, they were divided into two groups: normal and moderate.

Dubowitz Neurological Examination provides a neurological evaluation of preterm and term newborns. The test evaluates the infant in six areas, including neurological and neurobehavioral components, in correlation with brain ultrasonography findings, and determines the presence of neurological problems in the infant or whether the infant is at risk for neurological issues. The examination consists of 34 items: muscle tone, tone patterns, reflexes, movements, abnormal signs, and behavior. The 5th and 10th percentiles are used as cut-off points for scoring each item. An item falling above the 10th percentile is given 1 point, 0.5 points are awarded for scores between the 5th and 10th percentiles, and 0 points are assigned for scores below the 5th percentile. The total possible score is 34. In our study, we divided newborns into three groups according to cut-off scores: low, moderate, and high exposure [12, 13].

Care Participation Scale was developed to evaluate mothers' participation in the care of their infants during their stay in the NICU. The highest score that can be obtained from the scale is 19, while the lowest score is 0. An increase in the total score indicates that a mother's participation in the care of her infant is increasing [14].

The Edinburgh Postpartum Depression Scale (EPDS) is intended to determine women's risk of depression that may occur in the postpartum period. The highest score that can be obtained from the scale is 30, while the lowest score is 0. A mother with 13 points or more is considered at risk for postpartum depression [15].

Quality of Life Test Short Form-36 (SF-36) was developed by the Rand Corporation in 1992 to assess quality of life. The scale consists of 36 items evaluating the quality of life in

eight dimensions: physical function (10 items), social function (2 items), role limitations due to physical problems (4 items), role limitations due to emotional problems (3 items), mental health (5 items), energy/vitality (4 items), body pain (2 items), and general health perception (5 items) [16].

State-Trait Anxiety Inventory (STAI) was developed by Spielberger et al. to evaluate state and trait anxiety. The scores obtained from both scales range from 20 to 80. As the score increases, the individual's anxiety also increases [17].

Statistical Analysis

Data were analyzed using SPSS version 25.0 statistical software for Windows. The power of the study was found to be 0.9281, the effect size was 0.5 (medium), and the alpha value (α) was 0.05, as determined using G*Power software. Measured variables were expressed as mean \pm standard deviation ($X \pm SD$). Differences in parental involvement in care, depression, quality of life, and anxiety levels, as well as infant grouping according to Apgar and Dubowitz scores, were analyzed using independent samples t-tests and one-way ANOVA. All tests were conducted at a 95% confidence level ($p < 0.05$).

Ethical Approval

This study was approved by the Ethics Committee of Süleyman Demirel University, Faculty of Medicine (Date: 2020-02-06, No: 72867572.050.01.04-17).

Results

During the study period, 47 infants met the initial inclusion criteria. Four infants who could not undergo neurological examinations within the first 6 to 48 hours of life, two mothers who could not attend to the care of their infants due to health problems, and one infant who died were excluded from the study. Forty infants (26 boys and 14 girls) who were born at 37 to 40 weeks of gestation and met the inclusion criteria, along with their parents, were included in the study. Demographic information about the parents and the mean data for the infants are presented in Table 1. Maternal care and psychological outcomes classified according to the 5-minute Apgar score are presented in Table 2. When evaluating parents'

participation in care, depression, quality of life, and anxiety levels, postpartum depression ($p < 0.001$), physical function ($p < 0.001$), physical role difficulty ($p < 0.001$), energy and vitality ($p < 0.001$), mental health ($p < 0.001$), social functionality ($p = 0.018$), pain ($p < 0.001$), and general health ($p = 0.033$) were

Table 1. Demographic information of parents participating in the study and average data of infants

		n (%)	X \pm SD
Mother's Age	25 years and under	19 (47.5)	27.6 \pm 6.4
	26-35 years	15 (35.5)	
	36 years and older	6 (15)	
Father's Age	25 years and under	8 (20)	32.7 \pm 7.6
	26-35 years	22 (55)	
	36 years and older	10 (25)	
Marital status	Married (Official Married)	39 (97.5)	
	Living Separately	1 (2.5)	
Mother's education level	Primary school	15 (37.5)	
	Middle school	7 (17.5)	
	High school	13 (32.5)	
	University and above	5 (12.5)	
Father's education level	Primary school	11 (27.5)	
	Middle school	8 (20)	
	High school	15 (37.5)	
	University and above	6 (15)	
Gestational age (weeks)			37.51 \pm 0.79
1-minute Apgar score			6.12 \pm 1.60
5-minute Apgar score			7.05 \pm 1.29
Birth weight (gr)			2033.30 \pm 425.67
Birth length (cm)			44.50 \pm 3.21
Head circumference (cm)			31.18 \pm 2.33
Length of stay in NICU (days)			24.67 \pm 11.25
Total		40 (100)	

X: Mean; SD: Standard Deviation; Continuous variables described as X \pm SD and binary variables described as n (%), NICU: Neonatal Intensive Care Unit

Table 2. Evaluation of parents' care participation, depression, quality of life, and anxiety levels according to the 5th minute Apgar score of the infants participating in the study

5-minute Apgar Score	4-6 Moderate (n=11) X \pm SD	7-10 Normal (n=29) X \pm SD	t	P value
Participation in care (0-19 points)	12.09 \pm 2.11	12.03 \pm 1.47	0.095	0.924
Depression (0-30 points)	21.27 \pm 2.72	15.86 \pm 3.11	5.066	<0.001
SF-36 Physical function (0-100 points)	49.55 \pm 14.22	88.45 \pm 10.61	-9.412	<0.001
SF-36 Physical role difficulty (0-100 points)	20.45 \pm 15.07	62.93 \pm 28.04	-4.744	<0.001
SF-36 Emotional role difficulty (0-100 points)	21.19 \pm 16.80	32.17 \pm 20.86	-1.560	0.127
SF-36 Energy/Vitality (0-100 points)	16.36 \pm 7.44	52.93 \pm 20.37	-5.768	<0.001
SF-36 Mental health (0-100 points)	30.91 \pm 10.74	65.10 \pm 16.79	-6.255	<0.001
SF-36 Social functioning (0-100 points)	37.50 \pm 11.18	50.00 \pm 15.30	-2.462	*0.018
SF-36 Pain (0-100 points)	37.50 \pm 11.93	68.28 \pm 20.74	-4.615	<0.001
SF-36 General health perception (0-100 points)	29.55 \pm 10.11	38.45 \pm 13.50	-1.980	*0.033
State Anxiety (20-80 points)	46.55 \pm 6.34	44.66 \pm 4.56	1.047	0.302
Trait Anxiety (20-80 points)	43.91 \pm 5.08	42.14 \pm 4.63	1.051	0.300

X: mean; SD: Standard Deviation; SF-36: Quality of Life Test Short Form-36
An Independent Sample t-test was used.
*p<0.05

Table 3. Evaluation of parents’ care participation, depression, quality of life, and anxiety levels according to the severity of neurologic impact (dubowitz scale) of infants participating in the study

Severity of Neurologic Impact	High (n=4) X ± SD	Moderate (n=10) X ± SD	Low (n=26) X ± SD	f	P value
Participation in care (0-19 points)	10.75 ± 1.70	12.30 ± 1.94	12.15 ± 1.48	1.444	0.249
Depression (0-30 points)	24.00 ± 2.16	19.30 ± 1.41	15.58 ± 3.16	19.431	<0.001
SF-36 Physical function (0-100 points)	36.25 ± 4.78	63.00 ±14.37	89.81 ± 9.94	53.972	<0.001
SF-36 Physical role difficulty (0-100 points)	12.50 ±14.43	30.00 ±15.81	65.38±28.35	12.657	<0.001
SF-36 Emotional role difficulty (0-100 points)	24.97 ±16.65	26.65 ±21.08	30.75 ±20.92	0.233	0.793
SF-36 Energy/Vitality (0-100 points)	8.75 ± 6.29	24.50 ± 7.61	55.19 ±20.22	20.396	<0.001
SF-36 Mental health (0-100 points)	21.00 ± 3.83	43.20 ±13.30	65.85 ±17.53	17.965	<0.001
SF-36 Social functioning (0-100 points)	28.13 ± 6.25	45.00 ± 8.74	50.00 ±16.20	4.247	0.022*
SF-36 Pain (0-100 points)	24.38 ±10.68	48.75 ± 6.03	69.52 ±21.59	13.045	<0.001
SF-36 General health perception (0-100 points)	23.75 ±14.93	34.50 ± 6.85	38.46 ±13.98	2.414	0.103
State Anxiety (20-80 points)	53.50 ± 2.51	43.60 ± 4.30	44.50 ± 4.54	5.407	<0.001
Trait Anxiety (20-80 points)	48.50 ± 4.43	42.60 ± 3.95	41.73 ± 4.59	4.045	0.026*

X: mean; SD: Standard Deviation; SF-36: Quality of Life Test Short Form-36
One-way ANOVA was used.
*p<0.05

found to be statistically significant. There was no difference in care participation and anxiety levels. The depression levels of mothers who had infants with an Apgar score of 4-6 at the 5th minute were higher than those in the other groups. Additionally, it was determined that the sub-dimensions of quality of life for mothers with infants who had an Apgar score of 7-10 at the 5th minute were more advanced than those in the other groups. Maternal care and psychological outcomes classified according to the level of severity of neurologic impact are presented in Table 3.

When the parents’ participation in care, depression, quality of life, and anxiety levels were evaluated according to the severity of the neurologic impact of the infants participating in the study: postpartum depression (p<0.001), trait anxiety (p<0.001), state anxiety (p=0.026), physical function (p<0.001), physical role difficulty (p<0.001), energy, vitality, vitality (p<0.001) 0.001), mental health (p<0.001), social functionality (p=0.022) and pain (p<0.001) dimensions were statistically significant. Depression, trait anxiety, and state anxiety levels of mothers with infants with high severity of neurologic impact: It has been determined that it is at an advanced level compared to mothers with infants with moderate and low severity of neurologic impact. It was determined that the sub-dimensions of quality of life of mothers with low and moderate levels of severity of neurologic impact were more advanced than those of mothers with infants with high severity of neurologic impact. It was found that there was no significant difference between the groups in terms of participation in care.

Discussion

Our study aimed to evaluate the participation in care, depression, quality of life, and anxiety levels of parents with a high-risk infant and to investigate whether these factors change according to the severity of the infant’s neurological impact. Our findings showed that the anxiety levels, quality of life, and depression parameters of parents with at-risk infants change according to the severity of neurological impact. On the other hand, it was concluded that parental involvement in care did not change.

Emotional and behavioral changes in parents of high-risk infants have been the subject of many studies. However, research on the psychosocial problems caused by the severity of the infant’s neurological impact on parents is limited in the literature. This study examined the anxiety levels, quality of life, and depression of mothers in the early period according to the level of severity of neurological impact in the group described as high-risk infants for the first time, along with the participation of parents in care. An infant’s unstable health status and high risk of neurodevelopmental delay and childhood disability are known to have a strong impact on parental stress and anxiety [18,19]. In our study, we demonstrated this neurodevelopmental risk using the 5th-minute Apgar score and Dubowitz score. We found that there was no difference in parental involvement and anxiety according to the infant’s Apgar score; however, we noted that parents of infants with low scores had higher depression scores. A study conducted in 2019 examined the risk factors for postpartum depression and showed that the length of labor and duration of epidural analgesia are significant risk factors for developing postpartum depression. Conversely, the relationship between the newborn’s Apgar score and postpartum depression was not significant [20]. Lucja et al. revealed that there was no significant relationship between attachment between mother and infant and the infant’s Apgar score [21]. However, it is noted that the Apgar scores of the infants in these studies were not very low. The Dubowitz assessment was preferred in our study because it encompasses various aspects of neurological function, providing a detailed profile of the infant’s neurological status with practical application. However, no evaluation of parents in terms of depression and other factors according to this scale has been made in the literature. In our study, while depression and anxiety scores were high among parents of infants with high and moderate severity of neurological impact, quality of life scores were low. According to a study similar to ours, the depression levels of mothers of infants with encephalopathy were found to be twice as high as those of mothers of other infants admitted to the NICU. However, contrary to the results of our study, no relationship was found between the severity of the disease and depression in this study

[3].

The postpartum maternal psychological state has been associated with negative outcomes for the newborn. Studies have shown that mothers with postpartum depression exhibit more negative and distant behaviors, have less contact with their babies, participate less in care, breastfeed for shorter durations, experience decreased breastfeeding confidence, and face increased breastfeeding difficulties [22, 23]. While there are many different approaches to supporting an infant's development in the NICU, it is important to include the family as part of the care and to support the parent-infant relationship [9]. When examining the effect of kangaroo care on parental outcomes, it has been shown to reduce anxiety and depressive symptoms while positively impacting parental trust and interaction with the infant [24].

Considering all of this, it is important to improve the mental health of parents with babies in the NICU, strengthen their relationships with their infants, and offer ample opportunities for meaningful experiences (such as breastfeeding, skin-to-skin holding, and talking/communicating with their babies) based on the infant's cues. This approach is essential for optimizing both short- and long-term outcomes for the newborn. Future research is needed to better understand which strategies are most effective in optimizing infant and parent health based on neonatal and family outcomes [6,10]. Unfortunately, our study had some limitations. Post-discharge evaluations were not repeated. Another limitation was the limited time the mothers spent in the intensive care unit. Additionally, parents of premature infants were not included in the study.

Conclusion

This study provides new insights into the factors that contribute to parents' psychological problems. In light of the findings of our study and the existing literature, the following conclusions can be drawn: The medical condition of the infant significantly affects the mental health of the parents. Having a neurologically high-risk infant can lead to anxiety and depression in the parents, independent of the severity of the neurological impact; however, the severity of these problems is influenced by the level of neurological impairment. On the other hand, it can be concluded that the neurological status of the infant does not affect the parent's participation in care in the short term.

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Scientific Responsibility Statement

The authors declare that they are responsible for the article's scientific content including study design, data collection, analysis and interpretation, writing, some of the main line, or all of the preparation and scientific review of the contents and approval of the final version of the article.

Animal and Human Rights Statement

All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

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Conflict of Interest

The authors declare that there is no conflict of interest.

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